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ABSTRACT

This final report describes a one-year qualitative research study that explores service coordination to children with emotional or behavioral disorders (EBD) and their families. First, the project's conceptual framework, an ecological approach, is briefly explained. Next, the concept of service coordination is discussed, noting the role of the service coordinator and the lack of published studies on service coordination. Third, the rationale for employing qualitative methodology is offered. The study involved a questionnaire, interviews, and focus group sessions with eight parents of children with disabilities and six professionals (nominated by the parents). Results are reported in terms of family and child demographics, child placement history, and professional disciplines represented in the group. Findings suggest that the extent to which service coordination is effective may depend upon the interaction of three primary factors: (1) personal characteristics of the professionals working with the family; (2) characteristics of the organization in which the professional is employed; and (3) characteristics of the larger community system. The study identified personal characteristics of professionals that either facilitated or hindered effective service coordination as well as intraorganizational and interorganizational factors that facilitated or hindered service coordination. The Family Support Questionnaire is appended. (Contains 16 references.) (DB)

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Qualitative Investigation of Effective Service Coordination for Children and Youth with Emotional and Behavioral Disorders

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Qualitative Investigation of Effective Service Coordination for Children and Youth with Emotional and Behavioral Disorders

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Final Report

With the current emphasis on collaboration and integration of support services that rely on systematic service coordination to assist parents to navigate multiple categorical systems to ensure the success of their children at home, school, and in the community, it becomes imperative to gain an understanding of the characteristics of effective service coordination that increase the chances for success of these community efforts. This one year research project was designed to explore the construct of service coordination in order to understand better the microlevel and macrolevel factors that affect the provision of effective service coordination to children with emotional or behavioral disorders (EBD) and their families. The anticipated outcome was to develop a grounded theory of effective service coordination, guided by the information and insights provided by parents of children with EBD and the professionals parents nominated as effective in assisting them to coordinate services for their child and family.

This report provides an overview of the conceptual framework for understanding the importance of examining what constitutes effective service coordination and the rationale for utilizing qualitative research methods to move toward a more complete understanding of what effective service coordination really means. We then describe the research design, how the study was implemented, the extent to which project objectives were met, and the results of the inquiry. Implications for future research and the impact these findings may have on community efforts to develop, implement, and evaluate child-centered and family-focused systems of support for children with EBD and their families are discussed.

Conceptual Framework

During the past two decades, published reports have documented that the categorical approaches to assessment and treatment of children and youth with emotional and behavioral disorders (EBD) have produced unacceptably poor outcomes (Joint Commission on the Mental Health of Children, 1969; Knitzer, 1982; Wagner, 1992, 1995). As a result of the largely unsuccessful, isolated efforts of the categorical systems, an ecological orientation to understanding the causes of EBD and providing services to children and youth at all developmental stages is being promoted across the special education, mental health, child welfare, health, and juvenile justice systems (Forness, 1988; Lehman & Irvin, 1996; Leone, 1990; Nelson, Rutherford, & Wolford, 1996; View & Amos, 1994).

Ecological Approach

An ecological approach posits that the most important influence on a child is the family (Bronfenbrenner, 1979). In turn, children and families are interactive members of a larger system of social institutions, such as school, the work place, community health, community leisure, and child care services. The ecological model of understanding and supporting children and youth with EBD assumes the interactive and interrelated nature of children and family relationships, within the context of their social environments (e.g., school and community). Therefore, an ecological orientation promotes service delivery that is focused on the individual child and family, within the context of their social networks. The "intervention" or "treatment" within an ecological approach is more appropriately described as "support" that is child-centered and family-focused.

Children and youth with EBD are most often in need of services from more than one of the categorical systems (i.e., education, mental health, juvenile justice, child welfare). Therefore, to effectively support the child in the context of the family and community, these systems must collaborate and coordinate at the macrolevel (organizational level) and microlevel (direct service level) of the systems. The term "service integration" is commonly used to describe this ecological approach to supporting children and youth with EBD and their families (Nelson & Pearson, 1991). Theoretically, the essential direct service role within an effective, multisystems effort is that of the "service coordinator."

Service Coordination

The service coordinator is considered the key role in a community system that provides a coordinated and integrated system of support (Behar, 1985; Stroul & Friedman, 1986). Theoretically, within a community system of support, the service coordinator assists the parent(s)/guardian(s) to successfully plan, implement, and monitor service delivery. The service coordinator proactively works with the parent(s)/guardian(s), child with EBD, and paid and unpaid individuals in the family's support network to (a) determine the nature of the adjustment problem, (b) assist in identifying child and family goals, (c) link the child and family with the formal and informal services and supports appropriate to address each goal, (d) monitor and evaluate the delivery of services and child and family progress toward goals, (e) advocate (i.e., intervene on behalf of the child and family), (f) provide information to parents regarding where to find resources, and (g) coach parents regarding how to access services and effectively communicate their ideas and concerns about their child to school personnel, service providers, and others who are involved with their child and family (Early & Poertner, 1995). The common goal of the service coordinator, child, and parent(s)/guardian(s) is to enable the child to function as successfully as possible at home, school, work, and in the community.

In order for the service coordinator to be effective, Friesen and Briggs (1995) describe structural and organizational elements that must be present. The organizational and interorganizational policies and interpersonal relationships across systems can enhance or limit the effectiveness of the service coordinator. Theoretically, the in-depth examination of what constitutes effective service coordination would include identifying these organizational, interorganizational, and interpersonal characteristics. Further, the perspectives of the consumers of services and providers of direct services would offer

important information regarding the strengths and weaknesses of a community support system.

Except for a small number of program evaluations of community-based integrated and wraparound service efforts that rely on service coordination as the essential direct service role (Burchard, Burchard, Sewell, & VanDenberg, 1993; Illback, Sanders, & Birkby, 1995; Jordan & Ichinose, 1992) and one statewide survey of parents in which there was a positive correlation between the number of service coordination functions received and parent satisfaction with family quality of life (Lehman & Irvin, 1996), there are virtually no published studies that undertake an in-depth examination of the nature of effective service coordination from parents' perspectives. Findings from this study provide information that may assist state and local communities to systematically design coordinated systems of support that incorporate the macrolevel (systems level) and microlevel (direct service level) elements that appear to enhance the ability of the service coordinator to effectively support children and youth with EBD and their families. Results provide knowledge that may be used to design and implement a more extensive examination of intraorganizational (within the organization) and interorganizational (between organizations) factors that may be modified to support the implementation of more effective service coordination and support for this group of children, youth, and families.

Rationale for Employing Qualitative Methodology

Prior to this study, research examining what constitutes effective service coordination for children and youth with EBD consisted primarily of the evaluations of programs designed to service youth with the most severe emotional disturbances, utilizing community systems of care approaches, with wraparound types of service delivery (Burchard, et. al., 1993; Greenley & Robicheck, 1991). These program evaluations included both quantitative and qualitative approaches to measure the impact of specific programs on child and family outcomes, especially the extent to which such efforts reduced out-of-home placement of children and youth in more restrictive settings. Evaluation findings have provided important information about the need for administrative structures that empower service coordinators (case managers, resource coordinators) to effectively support the children and families to whom they are responsible.

One limitation of these efforts is that the definition of positive outcomes and the development of measures of success have been generated mostly by professionals within the categorical systems, especially the mental health system. A second limitation is that the children, youth, and parents have had little or no voice in deciding what constitutes effective service delivery and successful outcomes. Historically, educational, mental health, and social service professionals have assumed that specialized professionals know what children and families need in order for children with disabilities to succeed at school, home, and in the community. This assumption is being challenged through litigation on behalf of children with disabilities (Soler & Shauffer, 1991), parent grass roots organizing and political action (Federation of Families for Children's Mental Health, 1992), and by the growing recognition by some professionals that such an assumption is often counterproductive to the success of service delivery.

The shift toward child-centered and family-focused service delivery is still in its infancy stages. With this shift comes the need to increase research efforts which include

child and parent perspectives in order to understand the day to day reality of what constitutes effective assistance. Qualitative or "naturalistic" inquiry allows for an in-depth exploration of individual perspectives, with constant comparisons of the themes that emerge throughout the course of data collection. These procedures are flexible and exploratory, allowing the researcher to discover new factors of interest and new relationships among factors (Stainback & Stainback, 1984). Qualitative methods allow the researcher to explore a phenomenon by taking into account the (a) systems or environment of which the subject is a part, and (b) perspectives of the individual of interest. The qualitative research methodology, more than any other method, seeks and is driven by the perspective of the individual the researcher is attempting to understand (Edgerton, 1984). In this study, the perspectives of the parents and the professionals providing service coordination were sought to develop a better understanding of what effective service coordination means for parents who are ultimately responsible for ensuring the well-being of their children and family on a daily basis.

We sought to obtain information from the "insider's" point of view. Qualitative methods are best suited to this purpose. In recent years, researchers in the area of disability and special education have utilized qualitative methods to understand the perspectives of people with disabilities and their families (Bogdan & Taylor, 1982; Ferguson, Ferguson, & Taylor, 1992). This exploratory study was conducted by employing qualitative research methods.

Design

This section provides a description of each element of the research design. These components include (a) selection of participants, (b) instrumentation, (c) validity and reliability, (d) data collection procedures, and (d) data analysis.

Participants

Purposive sampling of parent and professional participants took place to (a) ensure participants were those who had received service coordination and reported that the assistance they received was effective and (b) to maximize variation among child and family participants. Unlike sampling for studies that employ statistical analysis in which large, randomized samples are required to facilitate generalization, sampling for qualitative studies seeks to maximize information through selection of a small number of "information rich" cases. This study employed maximum variation sampling methods, which are recommended for heterogeneous populations, in which cases are very different from each other (Lincoln & Guba, 1985; Patton, 1990). We explored effective service coordination across a wide range of child age, disability categories, and family characteristics.

Respondent Pool

In naturalistic research, quantitative methods are sometimes used to obtain a broad preliminary picture of typical and atypical cases and a map of where the outliers may be found in order to facilitate more in-depth investigation (Erlandson, Harris, Skipper, & Allen, 1993). For the purposes of this study, the pool of potential respondents was 26 parents whose demographic data from the Family Support Survey matched the criteria for selection. The following criteria were used to select the pool of respondents:

1. Parents who completed Part IV (Appendix A) of the Family Support Survey (i.e., the section specifically related to service coordination activities).

2. Parents who stated they received at least 2 of the 7 types of help related to service coordination.

3. Parents who stated they were either (a) somewhat successful; (b) successful; or (c) very successful in getting the help their child and family needed from their child's school or other organizations.

We reviewed survey data and sorted descriptive data for the pool of respondents to ensure a cross section of child characteristics (i.e., age, disability label(s), gender, ethnicity), family demographics (e.g., annual income, one or two parent family, level of education), and that families involved in community service programs which provided "integrated" types of service delivery were included. After this level of selection was completed, we compiled a list of survey ID numbers for the second level of selection. The OFSN staff person then matched this list with each parent's name and address in the Family Support Survey database. In order to maintain confidentiality, the OFSN staff person mailed a "request to participate" letter that was prepared by the project staff to each parent on the level two list (Appendix B). The letter included a description of the purpose of the research project, outline of the data collection procedures, and approximate time parents would be committing should they decide to participate. In addition, the mailing included a response form, permission to be contacted by project staff, and instructions for completing and returning the form for those interested in being included as participants.

A total of 12 parents returned the initial letters and indicated their interest in participating in the study. Within 1 week after receiving the returned and signed letters of interest, we contacted each parent by telephone. We anticipated that from 8 to 12 parents would become engaged in the study. From the group of 12 families, 8 parents made up the sample for the study. This number is within the range adequate to sample a particular population or topic and was manageable within the budgetary restrictions and limitations of this one year study.

Other Research Participants

During semi-structured interviews with parent participants, each parent was asked to nominate a professional who they considered helpful in providing service coordination for their child and family. Each of the 8 parents nominated at least one professional. Of the 8 professionals who were nominated, 6 were able to be located and were interviewed during the data collection procedure.

Instrumentation

In qualitative research, the primary data collection instrument is the researcher (Lincoln & Guba, 1985). Data collection methods included conducting (a) a focus group with parent representatives from the OFSN, (b) semi-structured interviews with 8 parents and 6 nominated professionals, and (c) field notes. The focus group was structured by utilizing a pre-established protocol as a guide to ensure that focus group goals were accomplished. Interview protocols were developed for the initial semi-structured parent and professional interviews (Appendix C). As interviews progressed, the protocol was modified to reflect findings from analysis of interview transcripts.

Ensuring Trustworthiness

Within the context of qualitative research, reliability of the data and validity of research findings is referred to as the extent to which the findings are considered trustworthy. The strategy of triangulation (Erlandson, Harris, & Allen, 1993) was employed in this study to constantly test the reliability of the data and the validity of our findings. For the purposes of this study, triangulation occurred across data sources (i.e., interviews with parents and professionals), researcher reflexive notes, and review of agency procedural documents and program descriptions that were accessible in some cases.

The process was one of seeking inconsistencies in the data and searching for the sources of the inconsistencies through further data collection. In addition, the faculty advisor reviewed a sample of interview transcripts. The faculty advisor and student researcher analyzed and discussed the selection of coding categories and coding of data, and compared and discussed their notes and comments regarding their separate analyses of the data. The researcher utilized a modified version of a case analysis meeting summary form (Miles & Huberman, 1994) to summarize case analysis meetings with the faculty advisor (Appendix C).

Formal and informal member checks with participants were conducted as a third method of ensuring trustworthiness. Throughout the course of data collection and analysis, the researcher contacted participants by telephone to check their reactions to her analysis and to clarify questions and responses as they emerged. In addition, at the conclusion of the data collection procedure, a preliminary report was mailed to each participant to elicit final feedback. One parent participant responded to the final request for feedback. The parent mailed her feedback to the researcher. The parent agreed with the researcher's findings and added pertinent information specific to 6 stated themes. This information provided a more in-depth perspective regarding the characteristics of professionals and systems that either facilitate or present barriers to effective service coordination. The feedback was incorporated into the final analysis.

Data Collection Procedure

Data collection was conducted solely by the student researcher, with the exception of focus group observation notes written by project team members. The semi-structured interviews with 8 parents and 6 professionals were conducted in the homes of the families, offices of 4 professionals, home of 1 professional, and at Teaching Research Division with 1

professional. The focus group and in-depth interviews were approximately 1.5 to 2 hours in length, audiotaped, and transcribed verbatim.

Focus group data were analyzed prior to conducting interviews since the information was employed to ensure the researcher's interview protocol covered all elements of what constituted effective service coordination (e.g., theory and practice from the literature and parent/parent and child advocate perspectives from within Oregon). One in-depth interview was conducted with each respondent. Interviews alternated between parent and professional, depending upon findings from continuous analysis of transcripts. Immediately after each interview was completed, transcription and data analysis took place in order to ensure accurate coding and categorization to recognize emerging themes and direct subsequent data collection activities.

Analysis

Analysis of qualitative data took place throughout the process of data collection. Marshall and Rossman (1989) describe this procedure as follows:

> *Data analysis is the process of bringing order, structure, and meaning to the mass of collected data...It does not proceed in a linear fashion; it is not neat. Qualitative data analysis is a search for general statements about relationships among categories of data; it builds grounded theory* (p. 112).

Grounded theory is theory that follows from data rather than preceding data (Erlandson, Harris, Skipper, & Allen, 1993). In this study, the researcher explored family service coordination to discover relationships between parent and service coordinator experiences and agency and community systems and practices. Analysis of data occurred through systematic coding of categories, clustering of those categories, and constant comparison of statements and researcher experiences with participants as data collection and analysis progressed. This process lead to the development of grounded theories of what constituted effective family service coordination within the context of the current dominant systems, which resulted in an operational definition of family service coordination as it may occur within integrated community systems for children with EBD and their families. These analyses and implications for systems change are reported in the Results and Summary sections of this report.

Data analysis and management were facilitated by using the qualitative computer software ATLAS / Ti (Muhr, 1994). This program was utilized to analyze and interpret interview transcripts and researcher memos. All relevant information was included in one hermeneutic unit. The researcher utilized the program to code, categorize, cluster, and identify relationships within and between participant transcript data and researcher memos.

Results

The purpose of this section is to present the results of the study. These results are reported by (a) describing the characteristics of the children and youth of interest, parent and professional participants, and (b) presenting findings from the study.

Description of Children and Respondents

In order to understand better what constitutes effective family service coordination, interviews were conducted with parents and professionals nominated as helpful in providing the functions of service coordination. Parent participants were purposively selected to ensure a range of child and family characteristics. Professionals were selected based solely upon parent nominations. We provide a summary of child and family characteristics and a brief description of professional participants in order to provide a frame of reference for understanding the operational definitions of effective family service coordination resulting from the synthesis of data.

Family and Child Demographics

As stated previously, a total of 8 families participated in the study. Family demographics included geographic location, annual income, one or two parent household, employment status, parent education, and number of children at home. There were 6 families from urban communities and 2 from rural communities. Family annual income ranged from less than $10,000 to $60,000, with 6 families earning $20,000 or less during the past year. Five families were headed by single mothers. There were 3 two-parent households. Four of the 5 single mothers worked full-time outside of the home. Six of the 8 parent participants graduated from high school only, 1 attended high school and did not graduate, and 1 parent earned a graduate degree. Four families consisted of more than 1 child living at home and 4 had only the child with EBD living at home.

Child demographics included age, biological or adopted children, gender, ethnicity, disability classifications, and placement history. Child ages ranged from 5 to 18 years (1 five years, 1 six years, 1 ten years, 1twelve years, 2 fifteen years,1 sixteen years, 1 eighteen years). Two of the children were adopted when they were toddlers. Seven children were Caucasian and 1was Latino. Of the 7 boys and 1 girl in the study, only one child, a six year old boy, had only one disability classification. In contrast, a 5 year old boy carries five disability classifications. Table 1 presents the total number of children represented who had each of the 16 disability classifications. The oldest youth, age 18, had 9 disability labels. The 6 remaining children carried between 4 and 6 disability classifications. Table 2 presents child age and disability classifications for each of the 8 children and youth represented in the study.

TABLE 1. Total Disability Classifications for Children Represented

Classification	Number of Children
Conduct disorder	5
Seriously Emotional Disturbance	5
Learning Disability	4
Developmental Disability	4
Oppositional Defiant Disorder	4
Attention Deficit Hyperactivity Disorder	4
Schizophrenia	2
Post Traumatic Stress Syndrome	3
Childhood Depression	2
Attention Deficit Disorder	2
Attachment Disorder	1
Anxiety Disorder	1
Chronic Depression	1
Autism	1
Fetal Alcohol Syndrome	1
Sex Offender	1

N = 8

TABLE 2. Child Age and Disability Classifications by Child

child 1: 1 classification: (age 6, male, SED)

child 2: 2 classifications: (age15 female, CD, LD)

child 3: 4 classifications: (age 16, male, DD, LD, Schizophrenia, SED)

child 4: 5 classifications: (age 5, male, Childhood Depression, ODD, Schizophrenia, SED, PTSS)

child 5: 6 classifications (age 10, male, Childhood Depression, CD, DD, LD, ODD, SED, PTSS)

child 6: 6 classifications (age 12, male, ADHD, Autism, CD, DD, Sex Offender, Fetal Alcohol syndrome

child 7: 6 classifications (age 15, male, ADD, ADHD, CD, ODD, SED, Attachment Disorder)

child 8: 9 classifications (age 18, male, Anxiety Disorder, ADD, ADHD, CD, DD, ODD, SED, Chronic Depression, PTSS)

Each child's placement history was recorded to gain an understanding of the characteristics of the children of interest and to document the extent of involvement each child and family had with the categorical systems. In addition, this information provided

verification of parent statements regarding involvement with multiple agencies and professionals across disciplines. Only 1 of the 8 children of interest had lived with the parent only. This child was the youngest of the 8 (age 5). The child had multiple diagnoses, lived with his mother, and had no siblings. The number of out-of-home placements for the remaining 7 children ranged from 2 to 6.

TABLE 3. Child Placement History

Child	Current Placement	Previous Placement
child 1	home (returned since survey)	foster home (mother-d & A)
child 2	home	2 times (relatives)
child 3	home	psych. hosp 90 days
child 4	home	none
child 5	home (res. trtmt since survey)	home, with mother, psych. hosp.
child 6	foster home (OYA)	home, relatives, foster home
child 7	home (since survey)	foster home-OSLC, detention, shelter care, father
child 8	home	psych. hosp, relatives, residential trmt center, juv. deten.

The combined Family Support Survey and parent interview data revealed the types of organizations that provided specific functions of family service coordination as defined in the literature and outlined in the survey (Appendix A). Table 4 presents the types of organizations and lists the functions of service coordination provided to each of the 8 children and families of interest.

TABLE 4. Organizations Providing Functions of Service Coordination and Services Provided

Child	Types of Organizations	Functions provided
child 1	County mental health	assessment,
child 2	School (home schooling now)	assessment, goals and written plan (IEP), monitoring
child 3	School, ESD, Physician	goals and written plan, link, provide information
child 4	ESD, AFS, SCF, Metro Family Services, Lutheran Family Services, County Mental Health	assessment, goals and written plan, link, monitor and evaluate, Provide information
child 5	Private psychologist, community non-profit counseling/social service program	assessment, monitor and evaluate, advocate by going to meetings with parent, provide information. teach self-advocacy
child 6	SCF, Juvenile Department, Trtment program for sex offenders, private therapist	assessment, goals and written plan
child 7	Treatment program with service coordination component	assessment, goal and written plan, link
child 8	County Mental Health (wraparound type of program), SCF, DD services	assessment, goal and written plan, monitor and evaluate, advocate by going to meeting with parent

Professional Disciplines Represented

The professionals nominated as effective in assisting parents to coordinate services for their child and family represented a range of disciplines and backgrounds. Of the 6 professionals who participated in the study, 3 were employed in programs that provided child-centered and family-focused service delivery (Stroul & Friedman, 1986). In the first case, the professional was employed as a service coordinator for a therapeutic foster care program. In the second case, the professional had been employed as a service coordinator for a system of care pilot project for children with EBD funded by the Robert Wood Johnson Foundation. In the third instance, the professional was employed as a family support worker for a countywide federally funded project to develop a community-based system of care. This professional was also the parent of a child with EBD. Other categorical systems represented by nominated professionals were a county drug and alcohol program, county juvenile services department, and state child welfare agency.

Findings from the Study

In this section the findings from the study are presented. The findings are reported in relation to research questions. The research questions were answered by analyzing interview transcripts and identifying emerging themes through continuous categorization, comparison, and clustering of phrases and statements within and between transcripts.

Overarching Research Question

What are the characteristics of effective service coordination for families who have children with emotional or behavioral disorders?

In order to identify the characteristics of effective service coordination, initial analysis of parent and professional transcripts of the in-depth interviews was conducted. As a result of initial coding of data from interview transcripts and subsequent clustering of codes and text phrases, we were able to identify cross-cutting themes as they emerged. Table 5 present the list of initial codes and the number of text phrases assigned to each category. The greatest number of phrases related to the categories of "information provided" and "systems limitations." When interpreting these data, we would suggest that the reader recognize that the initial coding process is an early step in analyzing these data. The collective value of all of the categories is that after initial coding we have an overview of the types of information that are available within the primary texts.

TABLE 5. Initial Coding Categories & Frequency of Text Assignment to Each Category

Coding Categories	Total Number of Related Responses
Information provided	59
Systems limitations	59
Community characteristics	37
Effective professional approaches	37
Family characteristics	31
Functions of service coordination received	31
Informal support	31
Initial contact between prof. and parent	31
Lessons learned	31
Parent feelings	31
Type of support received	29
Agency structure	29
Systems response to child's behavior	29
Child characteristics	29
Effective programs	22
Parent recommendations	19
Parent choice of who to contact	19
Parent communication with child	19
Placement changes	19
Predicting the future	19
Professional characteristics	19
Professional empathy	19
Professional feelings	19
Professional goals	19
Professional perceptions of the system	19
Professional perceptions of the child	19
Professional perceptions of the family	19
Professional training	19
Professional recommendations	19
Parent and child school experiences	19

As a result of continuous analysis, clustering of codes, and member checks, three primary themes emerged to more fully understand the factors that may help determine what constitutes effective family service coordination. The study suggests that the extent to which service coordination is effective may depend upon the interaction of 3 primary factors: (a) personal characteristics of the professionals working with the family, (b) characteristics of the organization in which the professional is employed (intraorganizational characteristics), and (c) characteristics of the larger community system (interorganizational or systems and community characteristics). These factors in turn may be affected by child and family characteristics. Analyses of interview transcripts with the 8 parent participants and 6 nominated professionals revealed professional, organizational, and interorganizational factors that either facilitated or presented barriers to providing effective assistance to these children and their families.

Personal Characteristics of Professionals that Facilitated Effective Service Coordination

There were a number of personal characteristics of professionals that parents identified and professionals presented when interviewed that appear to affect parent perceptions that the professionals were effective. These included:

- Regarded the parent as a resource (i.e., believed the parent had insights and information that was useful).
- Assumed the parent had the best interests of the child in mind and respected or tried to understand the parent's point of view, even when the professional and parent disagreed.
- Pragmatic approach, provided timely and practical assistance based on priorities set by the parent and child.
- Available when needed (either by telephone or in person).
- Genuinely cared about the child, parent(s), and family.
- Visited the home and spent time with the family (i.e., understood what home life was like).
- Built and sustained a positive relationship with the child.

The following excerpts from interview transcripts provide a parent's (excerpt 1) and a professional's (excerpt 2) statements which reflect the general flavor of parent and professional comments regarding what constitutes positive attributes of effective service coordination.

> *She understood the problem and she worked with it. She knew and was real clear what all the troubled pieces were and she was very caring. And also, she was very good at being where the buck stops...she was available 24 hours a day. If I needed her, I could call her...and so could Chris [pseudonym for child]. So communication was absolutely there...because all the professionals were talking to each other.*
>
> [Parent description of a professional whose role was to provide service coordination]

> *There has to be a relationship. We're Talking about people's lives and we have to develop that level of trust that is gonna give people permission to make changes. If they don't trust what you're doing is . in their best interest, why would anybody do anything that you recommend? The government is a pretty big barrier in the work we do. I would never trust anybody from the government ya know---- coming in telling me what to do. I would also hope that person coming in is knowledgeable and is really going to be there to help. It's*

not gonna be another awful bureaucratic experience where somebody is telling [the child] what a worthless kid I am because I never figured out how to jump through the hoops. Whether these words are ever used, the message is clear. The message is really clear.
[Juvenile probation counselor employed by a county juvenile department]

Personal Characteristics of Professionals that Presented Barriers to Effective Service Coordination

In contrast to the professionals they nominated as effective, parents described responses made by professionals from education, mental health, child welfare, and the juvenile justice system that they considered barriers to providing effective support for their child and family. A pattern that emerged as data were analyzed was that when parents knew their child had special needs early in their development, professionals often did not recognize or respond appropriately to these early signs that the child may develop serious emotional or behavioral problems. In addition, when seeking assistance to deal with their child's problem behaviors, parents were sometimes told by professionals that they could not provide support because the parent was already doing everything that was possible. An important indicator that professionals were not effective in supporting parents appeared to be parent perceptions that they were being judged by the professional as the source of their child's problem. Another common theme was that often professionals within education, child welfare, and mental health were not aware of current information regarding specific disabilities and best practices for supporting children and families. Professional characteristics representing barriers included:

- Failed to act to assist the child when the child was young. Did not recognize and respond appropriately to early signs that the child may develop serious emotional or behavioral problems (parent reports regarding lack of assistance early on referred mostly to school personnel).

- Told parent(s) she/he could not help because the parent(s) were already doing everything possible.

- Parent(s) and child were often not considered the decision makers even when they were included in team meetings.

- Not familiar with current information regarding specific disabilities and best practices.

  ...for years we knew more (usually lots more) about attachment disorder than virtually anyone we worked with.
  [Parent statement of a "general barrier" to receiving effective support]

- Blamed and judged the parent(s) for the child's emotional or behavioral problems.

  They look at me as a controlling, overly involved parent
  [Parent describing school and mental health professionals]

Analysis of data from interviews with the profession participants revealed a number of common themes. These themes provide preliminary insights regarding the personal values and perceptions of these professionals who parents considered effective service coordinators. The 6 common themes were:

- Had a vision for how to support children from an early age.
- Expressed concern and caring for children and youth and empathy for parents.
- Stated that they were pragmatic and did what needed to be done, whether or not the task was expected as part of their job description.
- Consciously attended to not doing the work of other professionals.
- Searched for community resources that matched child and family needs.
- Identified the need for systems level changes.

Interorganizational and Intraorganizational factors that facilitated or presented barriers to receipt of effective family service coordination.

What are the characteristics of the local educational and social service systems that facilitate the provision of effectiveness service coordination or limit the nature and extent of service coordination provided to families who have children with emotional or behavioral disorders?

Characteristics that facilitated the provision of effective service coordination

- Programs that were designed to provide individualized, child-centered and family-focused service delivery (therapeutic foster care, with teams that the parent and service coordinator or case manager perceived as working well together [in good communication]).
- Support services that were designed as community systems, with the service coordination or case management role clearly defined to coordinate services across systems and act as an advocate for the child and family (based on the values and organizational principles of Stroul and Friedman's (1986) system of care.
- Categorical programs and departments that provided staff with the freedom to expand and modify their job responsibilities to include the activities and approaches they considered necessary to ensure the child and family received the support that matched their individual strengths and needs (supervisors that allowed flexibility and a certain level of autonomy). *[may been dependent upon the department head or program director's beliefs, values, and working relationship with the direct service professional]*

Characteristics that presented barriers to the provision of effective service coordination

- Support was often limited to the parent and child going to the professionals rather than the professionals going to the child and family (e.g., office visits rather than home visits).

- The child received services when she / he "fit the program."

- Lack of continuity of support when the child left a program or placement (pattern was that the family had to "start over").

- Parent and child generally were not the key decision-makers, even when they were included as team members. Most often the child was not considered an active team member by the professionals.

- There appeared to be a strong relationship between the extent to which the child or youth had become a serious behavior problem for the community or school and the amount and type of support received.

- The categorical systems were generally not proactive in addressing the needs of the children and their families (i.e., support was perceived as too little too late; the need for out-of-home placement may be related to receipt of services).

- There appeared to be a greater focus on the classification of the child's problem than on responding in a systematic way to the needs of the child and family.

- Lack of enough appropriate out-of-home resources (i.e, children and youth were "placed" based upon availability of "slots" / "beds".

- Widespread lack of transitional support when youth became age 18; parents felt they had little or no information about how to access the adult service system.

- Inflexible categorical rules and procedures.

> *...the same thing happened when our son went into a program here, and we tried to say we wanted to share information. [I told them] we want to give you this information so you can know what he is going to do. And I called them three times, and I said we want to set up a meeting to share information with you. And they said, we don't do that until they've been here at least four months.*
>
> [Parent description of her experience with residential treatment program professionals. [note: before the 4 month period ended the child had displayed the behaviors and characteristics the parent anticipated. She felt the staff did not know how to address the behaviors and needs of her son and was not interested in hearing what she had to say (e.g.,did not utilize the parent as a resource).]

Emerging Themes: Synthesis of Parent and Professional Perspectives

This section describes the themes and patterns that emerged as parent and professional interview data are analyzed and compared. The findings presented reflect factors that appear to facilitate or present barriers to the provision of effective service coordination. When analyzing parent and professional perceptions related to the provision of service coordination, professional perceptions appear to validate much of what parents believe facilitate or present barriers to accessing the assistance their child and family need The following themes have emerged:

I. Characteristics of professionals that may help define them as effective service coordinators

Effective professionals regard the parent as a resource who provides information and insights that are useful. These professionals also assume the parent has the best interests of the child in mind, even when the professional and parent disagree. They genuinely care about the child and are empathetic toward the parents. They believe in and are effective in building and sustaining positive relationships with the children and youth.

In terms of professional practice, effective professionals are generally available when needed. However, in more than one instance, parents recommended that there be someone to turn to on a twenty-four hour basis. These parents suggested that just knowing that such support is available may alleviate much of their stress, even if they never had to call for help. There was only one professional interviewed who considered herself to be available at any time, day or night. Effective professionals appear to be seen by parents and perceive themselves as very pragmatic. They provide timely and practical assistance based on priorities set by the parent and child. As one professional stated "I'm a doer. I just do what needs to be done."

The advocacy function was discussed by parents and professionals. One professional used the term "co-advocate" to describe how he and the parent work as a team to communicate effectively with professionals to access needed support and catalyze appropriate action by professionals. Each professional interviewed: (a) had a vision for how to support children from an early age; (b) searched for community resources to match what the child and family needed and; (c) identified the need for systems-level changes.

II. Parents and professionals perceived systems limitations that presented barriers to the provision of child-centered and family-focused coordinated support

The stories shared by parents reflect community systems that remain "agency-centered." For example, receipt of professional support appeared to depend upon the ability of the child and parent to go to the service provider (e.g., school, agency) rather than the professional coming to the child's home. In contrast, when parents described how support was provided by professionals they considered helpful, they spoke of the professional spending time in the home and knowing first hand what their family was like.

A second limitation of the system appeared to be the continuation of the traditional service delivery model based on the ability of the child to "fit into the program" rather than

tailoring the support plan to match the strengths and needs of the child. A related barrier may have been the lack of continuity of support when the child left the program (i.e., the family starts over). For example, when a family received what parents considered effective support, including the assistance of a service coordinator, upon completion of the program the service coordinator remained program-bound.

Generally, parents and nominated professionals perceived that the categorical systems did not respond effectively when children began to exhibit emotional and behavioral problems. In terms of the functions of service coordination provided to the families in this study, there appeared to be a greater focus on classification of the child's problem (e.g., formal evaluation and diagnosis) than responding in a systematic way to the needs of the child and family. For example, with the exception of one child, these children had been evaluated and labeled by multiple systems and had received very limited comprehensive service coordination since the initial onset of their emotional and behavioral difficulties.

Additional barriers were the dearth of appropriate resources for out-of-home placement (e.g., children placed where there is a "slot"). Further, of great concern to parents of older children was the lack of transitional support when a child becomes age 18 (e.g., little or no information for parents and youth about how to access adult services).

Defining Family Service Coordination

Results support the theoretical literature (Behar, 1985; Stroul & Friedman, 1986; Early & Poertner, 1995), findings from the Family Support study (Lehman, 1996), and evaluations of wraparound and integrated service delivery efforts (Burchard, Burchard, Sewell, & VanDenberg, 1993; Illback, Sanders, & Birkby, 1995; Jordan & Ichinose, 1992). The findings build upon the small but growing body of literature related to family service coordination. While the functions of service coordination reported in the literature appeared to be important to the parents and the professionals in this study, successful provision of the monitoring function and ability of the professional providing service coordination to have the flexibility and autonomy to be effective appeared to occur rarely for those professionals who worked within the confines of traditional organizational structures.

Theoretically, the common goal of the service coordinator, child, and parent(s)/guardian(s) is to enable the child to function as successfully as possible at home, school, work, and in the community. However, within local communities the lack of systems designed to be child-centered and family-focused appeared to prevent parents and professionals from accessing the resources the child and family needed when concerns were first identified. Therefore, from very early on the community system was unable to respond appropriately to support the child and family.

The effectiveness of the family service coordinator appears to depend upon three primary factors: (a) personal characteristics of the professionals working with the family, (b) characteristics of the organization in which the professional was employed (intraorganizational characteristics), and (c) characteristics of the larger community system (interorganizational or systems and community characteristics).

One factor which may have an impact on whether service coordination is effective is the match between the professional and the child and parent(s). This variable was not specifically explored in the study. However, findings suggest that there were attitudes and beliefs that were shared between parents and the professionals they nominated as helpful. These findings were discovered by analyzing the apparent relationship between parent perspectives about the characteristics of the professionals they believed were effective and those professionals' statements about how they accomplished their work with troubled children and families. These findings may be useful to identify individuals who may be good candidates for the role of service coordination. For example, individual beliefs and values about how to relate to children and parents who need assistance and how to work effectively within the categorical system , in spite of the system, could contribute to the effective provision of service coordination.

The definition of effective service coordination within a transformed community system of support must incorporate the macrolevel (systems level) elements that appear to contribute to effective provision of support (such as community support systems that are child and family driven rather than program driven, with easy and timely access and sufficient resources to meet the unique needs of each child and family) with microlevel (direct service) elements (such as personal and professional characteristics of those assigned the service coordination role, and training and coaching of individual child and family support teams).

Summary

The Family Service Coordination Study was designed to examine parent perceptions of what constitutes effective service coordination. What we discovered is that the professionals nominated by parents as providers of effective service coordination represented a wide range of professional disciplines. These included social service, juvenile justice, children's mental health, and drug and alcohol treatment disciplines. Within the limitations of the current community systems, it may well be that provision of effective support and assistance for parents, that ensures their child and family receive timely and appropriate services, is more a function of the personal characteristics and values of the individual direct service professionals than of the structure of the community system.

Even though legislation and best practices promote a child-centered and family-focused coordinated approach to service delivery at the local level, findings from this study suggest that the systems mandated to serve children and youth who have emotional or behavioral disorders continue to be more program-centered and agency-focused than child-centered and family-focused. However, there appears to be an ever growing philosophical shift taking place, bolstered by an increasingly influential parent and child advocacy movement. This shift toward an ecological orientation for supporting children with emotional and behavioral disorders and their families continues to influence efforts at the state and local level to transform categorical policies and programs that prevent the integration of systems and replace them with intraorganizational and interorganizational policies and programs that appear to facilitate the provision of comprehensive child-centered and family-focused community systems of support.

The findings from this study add to the small but growing knowledge base related to child-centered and family-focused approaches to providing services and support to children and youth with emotional and behavioral disorders. Preliminary findings from this study were presented at the Project Director's meeting (poster session), the University of South Florida's System of Care national research conference, Portland State University's Building on Family Strengths national conference, and the Virginia Commonwealth University, Medical College of Virginia's national conference on children's mental health. The first of two journal articles is being outlined and will be submitted by August 1997. In addition, a summary of findings will be reported in the Oregon Family Support Network newsletter which is distributed primary to professionals and families within Oregon.

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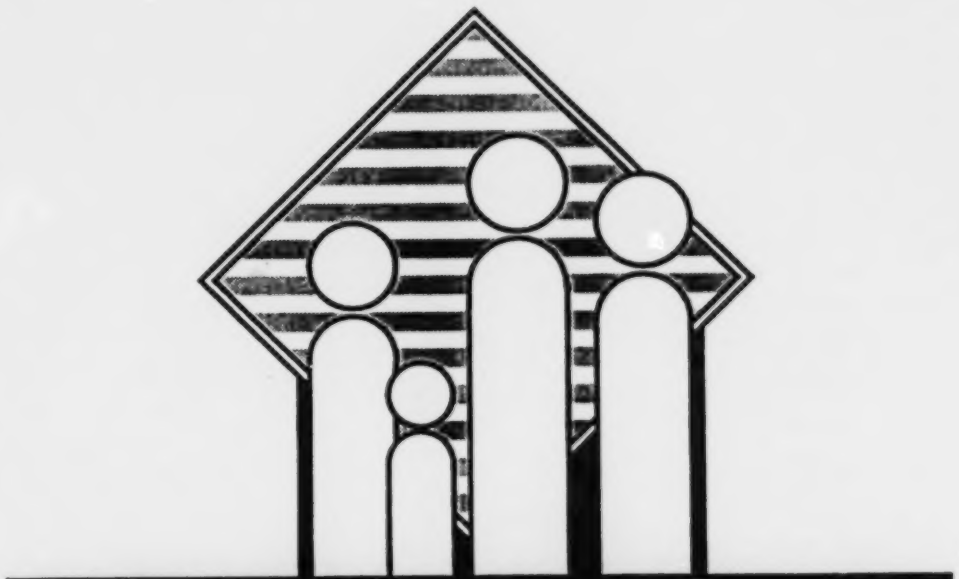
APPENDIX A

STUDY ID _____



FAMILY SUPPORT SURVEY

Return to:
Constance Lehman
Teaching Research Division
Western Oregon State College
Monmouth, OR 97361

INSTRUCTIONS FOR COMPLETING THIS QUESTIONNAIRE

Dear Parent,

Thank you again for taking the time to fill out this questionnaire! It should take about 30 minutes to complete. Please read the instructions carefully before answering the questions. By doing so, it will be easier to complete the survey.

- If you have more than one child who has an emotional or behavioral disability, please answer the questions for the child whose problems you consider more serious.
- If at any time you feel uncomfortable answering a question, you may stop filling out the questionnaire or skip to the next question.
- If you have any comments or wish to explain your answers to any questions, please feel free to write in the margins. Your comments will be taken into account.
- Answer the questions in the order they are presented.
- Instructions are given throughout the questionnaire. If the instructions ask for one answer or for more than one, please follow those instructions.
- When you have completed the questionnaire, return it in the enclosed pre-addressed and postage-paid envelope.
- Mail the enclosed pre-addressed and postage-paid post card separately from the questionnaire if you would like a summary of the results of the study.

Note: In about one month we will be mailing a shorter version of the questionnaire to a small number of parents, to find out how much the answers are the same a short time after the first questionnaire was completed. This will be a test of how good the questionnaire is, not a test of the people who respond to it. There is a possibility that you will be part of that group. If you receive the short version and do not wish to participate, please do not return the questionnaire. Again, responses will be completely confidential. Completing and returning the questionnaire will mean you consent to participate.

THANK YOU!

PLEASE RETURN YOUR COMPLETED QUESTIONNAIRE WITHIN ONE WEEK

Use the pre-addressed and postage-paid envelope to mail to:

Constance Lehman
Teaching Research Division
Western Oregon State College
Monmouth • Oregon • 97361

FAMILY SUPPORT QUESTIONNAIRE

STUDY ID _____

PART I: THIS SECTION ASKS ABOUT YOUR FAMILY.

1. In what county does your family live? _____ county

2. What is your relationship to your child with an emotional or behavioral disability? (Check one)
   - ___ mother 1
   - ___ stepmother 2
   - ___ father 3
   - ___ stepfather 4
   - ___ adoptive mother 5
   - ___ adoptive father 6
   - ___ sister 7
   - ___ brother 8
   - ___ grandmother 9
   - ___ grandfather 10
   - ___ foster mother 11
   - ___ foster father 12
   - ___ other(describe): 55 _____

3. Which of the following best describes your home? (Check answers in section "a" or in section "b")
   a. ___ Two parents in the home.
      (If you checked this answer, also check one of the following)
      - ___ mother & father 1
      - ___ mother & stepfather 2
      - ___ father & stepmother 3
      - ___ foster mother & foster father 4
      - ___ other (describe): _____ 55

   b. ___ One parent in the home
      (If you checked this answer, also check one of the following)
      - ___ mother only 1
      - ___ father only 2
      - ___ stepmother only 3
      - ___ stepfather only 4
      - ___ foster mother only 5
      - ___ foster father only 6
      - ___ other (describe): _____ 55

4. _____ Total number of adults (19 and older) living in your home, including yourself. (Write the number in the space)

5. Total number of children living with you in each of the following age groups, including your child with an emotional or behavioral disability.(If none, write "0" in the space)
   - _____under 5 years of age 1
   - _____5 to 12 2
   - _____13 to 18 3

6. Total number of people living with you in each of the following age groups who have emotional or behavioral disabilities, including your child with an emotional or behavioral disability. (If none, write "0" in the space)
   - _____under 5 years of age 1
   - _____5 to 12 2
   - _____13 to 18 3
   - _____19 and older 4

7. Your current age: _____ years

8. Your spouse / live-in partner's current age:
   - _____ years 1
   - _____ not applicable (no spouse/line-in partner) 888

9. What is the highest level of education you have completed? (Check one)
   - ___ Some high school or less 1
   - ___ High school diploma/GED 2
   - ___ Business or trade school 3
   - ___ Some college 4
   - ___ Associate degree 5
   - ___ Bachelors degree 6
   - ___ Some graduate school 7
   - ___ Graduate degree 8

10. What is the highest level of education your spouse/live-in partner has completed? (Check one)
    - ___ Some high school or less 1
    - ___ High school diploma/GED 2
    - ___ Business or trade school 3
    - ___ Some college 4
    - ___ Associate degree 5
    - ___ Bachelors degree 6
    - ___ Some graduate school 7
    - ___ Graduate degree 8
    - ___ Not applicable (no spouse/line-in partner) 888

11. Are you presently: (Check one)
    - ___ Employed part-time 1
    - ___ Employed full-time 2
    - ___ Unemployed 3
    - ___ Retired 4
    - ___ Full-time homemaker 5
    - ___ Other (describe):_____ 55

12. What is your race? (Check one)
    - ___ African American 1
    - ___ Asian American 2
    - ___ Pacific Islander 3
    - ___ Hispanic or Latino American 4
    - ___ Native American 5
    - ___ White 6
    - ___ Other (describe): _____ 55

13. Is your spouse/live-in partner presently: (Check one.)
    - ___ Employed part-time 1
    - ___ Employed full-time 2
    - ___ Unemployed 3
    - ___ Retired 4
    - ___ Full-time homemaker 5
    - ___ Other (describe): _____ 55
    - ___ Not applicable (no spouse/line-in partner) 888

14. What was your approximate family income from all sources before taxes in 1994? (Check one.)
    - ___ less than $10,000 1
    - ___ 10,000 - 19,999 2
    - ___ 20,000 - 29,999 3
    - ___ 30,000 - 39,999 4
    - ___ 40,000 - 49,999 5
    - ___ 50,000 - 59,999 6
    - ___ 60,000 - 69,999 7
    - ___ over 70,000 8

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PART II: THIS SECTION ASKS ABOUT YOUR CHILD WHO HAS AN EMOTIONAL OR BEHAVIORAL DISABILITY.

15. What is your child's sex?
(Check one) ___ Female ___ Male

16. What is your child's age?
(Write the number of years) _____ Years

17. What is your child's race? (Check one)
___ African American 1
___ Asian American 2
___ Pacific Islander 3
___ Hispanic or Latino American 4
___ Native American 5
___ White 6
___ Other (describe): _____ 55

18. You may have been given names for your child's problem. To the best of your knowledge, what are those names? (Check all that you remember)
___ Anxiety Disorder 1
___ Attention Deficit Disorder (ADD) 2
___ Attention Deficit Hyperactivity Disorder(ADHD) 3
___ Autism 4
___ Bipolar Disorder 5
___ Childhood Depression 6
___ Conduct Disorder 7
___ Developmental Disability 8
___ Learning Disability (LD) 9
___ Obsessive-compulsive Disorder 10
___ Oppositional Defiant Disorder 11
___ Schizophrenia 12
___ Seriously Emotionally Disturbed (SED) 13
___ Have not been given a name 14
___ Other (name) _____ 55

19. Where is your child living now? (Check one)
___ At home with you 1
___ With relatives 2
___ With friends 3
___ Foster home 4
___ Group home 5
___ Residential treatment center 6
___ Psychiatric hospital 7
___ Juvenile detention center 8
___ Other (describe): _____ 55
___ Don't know 777

20. In your opinion, how well is this living arrangement meeting your child's needs? (Check one)
___ NOT AT ALL WELL 1
___ SOMEWHAT WELL 2
___ WELL 3
___ VERY WELL 4

21. How many times has your child lived outside of your home because of her/his problems?
____ number of times (If never, write "0")

- **If "0" skip to question 22 at the top of of the next page.**
- **If one or more continue with question 21a in the next column.**

21a. In which places has your child lived?(Check all that apply)
___ With relatives 1
___ With friends 2
___ Foster home 3
___ Group home 4
___ Residential treatment center 5
___ Psychiatric hospital 6
___ Juvenile detention center 7
___ Other (describe): _____ 55

21b. Where is/was your child's current/most recent out-of-home placement? (Check one)
___ With relatives 1
___ With friends 2
___ Foster home 3
___ Group home 4
___ Residential treatment center 5
___ Psychiatric hospital 6
___ Juvenile detention center 7
___ Other (describe): _____ 55

- **If your child has returned home from the most recent out-of-home placement, continue to question 21c.**

- **If your child has not yet come home from the most recent out-of-home placement, go to question 22 at the top of next page.**

21c. When your child returned home from the most recent out-of-home placement, was there a paid professional (such as a family service coordinator or case manager) who worked with you to get help from the school and other agencies so that your child could succeed at home? (Check one)
___ YES **If "YES", continue to question 21d**
___ NO **If "NO", go to question 22 at the top of the next page**

21d. What agency did that professional work for? (Check one)
___ Residential treatment center 1
___ Psychiatric hospital 2
___ Juvenile corrections facility (e.g. McClaren, Hillcrest) 3
___ Juvenile department (probation office) 4
___ Children's Services Division (CSD) 5
___ School 6
___ Day treatment center 7
___ Private therapist or counselor 8
___ Other (specify): _____ 55
___ Don't know 777

21e. How helpful was the support you received from that professional (family service coordinator or case manager) in helping your child and family adjust to her/his being back home? (Check one)
___ NOT AT ALL HELPFUL 1
___ SOMEWHAT HELPFUL 2
___ HELPFUL 3
___ VERY HELPFUL 4

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22. What is your child's current school program? (Check all that apply)

___ Under school age 1
___ Pre-school program 2
___ full-time in regular education 3
___ full-time in special education 4
___ full-time in combined regular & special education 5
___ part-time in regular education only 6
___ part-time in special education only 7
___ part-time in combined regular & special education 8
___ residential treatment program school 9
___ day treatment program school 10
___ individual tutoring in school 11
___ individual tutoring at home 12
___ home schooling 13
___ not in any educational program 14
___ expelled or suspended 15
___ Other (describe):_____ 55

- **Answer questions 23 through 25 ONLY if your child is living with you at the present time.**
- **If your child is living outside of your home at the present time, go to question 26 in Part III.**

23. List the types of school and community activities in which your child participates (such as clubs, sports, church groups, etc.). Write "none" if she/he is not involved with any school or community activities at this time.

- _____
- _____
- _____

24. How often is your child directly involved in your family's daily chores and leisure activities? (Check one)

___ NOT AT ALL INVOLVED 1
___ SOMETIMES INVOLVED 2
___ USUALLY INVOLVED 3
___ ALWAYS INVOLVED 4

If you answered "NOT AT ALL INVOLVED," go to question 26 in Part III; otherwise answer question 25.

25. How do you feel about your child's involvement in your family's daily chores and leisure activities? (Check one)

___ NOT AT ALL POSITIVE 1
___ SOMETIMES POSITIVE 2
___ USUALLY POSITIVE 3
___ ALWAYS POSITIVE 4

PART III: THIS SECTION ASKS ABOUT WHO HELPS YOU WITH THE DAY TO DAY CHALLENGES OF RAISING YOUR CHILD WHO HAS AN EMOTIONAL OR BEHAVIORAL DISABILITY.

26. At this time, who are the most helpful when you need someone to talk to about the hassles and concerns of raising your child with an emotional or behavioral disability? Go down the list and check 3 answers only. Write a "1" for the most helpful person; a "2" for the second most helpful person; a "3" for the third most helpful person.

___ Your spouse / live-in partner 1
___ Child's grandparent 2
___ Your other children 3
___ Other family member 4
___ Friend 5
___ Neighbor 6
___ Co-worker 7
___ Your employer 8
___ Member of your religious group 9
___ Parent of a child with similar problems 10
___ Your child or family doctor 11
___ Private counselor or therapist 12
___ Community mental health counselor 13
___ Child's school teacher 14
___ Juvenile probation counselor 15
___ Children's Services Division (CSD) caseworker 16
___ Other professional (write job title or name of the place she/he works): 55

_____

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27. Check the types of support your family receives at this time and how helpful each is in meeting your family's needs. First, go down the list and check all the types of support your family receives at this time. Then, for those types of support you have checked, put another check in the appropriate column to the right to show how helpful each type of support is to your child and family.

Types of Support Received	Not at all helpful 1	Somewhat helpful 2	Helpful 3	Very helpful 4
❑ Baby sitting / respite care 1	❑	❑	❑	❑
❑ Financial assistance 2	❑	❑	❑	❑
❑ Transportation to meetings and community activities 3	❑	❑	❑	❑
❑ In-home help with your child 4	❑	❑	❑	❑
❑ In-home help with household chores 5	❑	❑	❑	❑
❑ Advice about how to manage your child's behaviors 6	❑	❑	❑	❑
❑ Information about legal rights 7	❑	❑	❑	❑
❑ Information about how to get services 8	❑	❑	❑	❑
❑ Someone to talk to 9	❑	❑	❑	❑
❑ Other (list type(s) of help): _____ 88	❑	❑	❑	❑
_____	❑	❑	❑	❑
_____	❑	❑	❑	❑
	❑	❑	❑	❑

28. Check the types of organizations that provided services to your child and family during the past year (since January 1994) and how helpful each has been in meeting your child and family's needs. First, go down the list and check all of the types of organizations that provided services to your child and family during the past year. Then, for those you have checked, put another check in the appropriate column to the right to show how helpful each has been to your child and family.

Types of Organizations	Not at all helpful 1	Somewhat helpful 2	Helpful 3	Very helpful 4
❑ School 1	❑	❑	❑	❑
❑ Adult and Family Services (AFS) 2	❑	❑	❑	❑
❑ Children's Services Div. (CSD) 3	❑	❑	❑	❑
❑ County Mental Health 4	❑	❑	❑	❑
❑ County Health Department 5	❑	❑	❑	❑
❑ Private Social Service Agency 6	❑	❑	❑	❑
❑ Private Counselor or Therapist 7	❑	❑	❑	❑
❑ Residential Treatment Center 8	❑	❑	❑	❑
❑ Day Treatment Program 9	❑	❑	❑	❑
❑ Psychiatric Hospital 10	❑	❑	❑	❑
❑ Family Doctor 11	❑	❑	❑	❑
❑ Employment Office 12	❑	❑	❑	❑
❑ Police Department 13	❑	❑	❑	❑
❑ Juvenile Department 14	❑	❑	❑	❑
❑ Community Recreation Center 15	❑	❑	❑	❑
❑ Religious Group 16	❑	❑	❑	❑
❑ Parent Support Group (parent-run) 17	❑	❑	❑	❑
❑ Statewide Family Support Org. 18	❑	❑	❑	❑
❑ Other (describe): _____ 55	❑	❑	❑	❑
_____	❑	❑	❑	❑
_____	❑	❑	❑	❑
_____	❑	❑	❑	❑

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>>>> GO TO NEXT PAGE >>>>

PART IV: THIS SECTION ASKS ABOUT PAID PROFESSIONALS AND HOW THEY SUPPORT YOU, YOUR CHILD, AND YOUR FAMILY.

29. Which of the following types of help do paid professionals provide for you and your family? (Check all that apply)

___ Help you figure out what your child's problem is and the type of help your child and family need. 1

___ Help you name goals for your child and your family and write them in a written plan of action. 2

___ Connect you with the services that can help you meet the needs of your child and family (such as parenting classes, health/medical services, counseling, housing assistance, financial help, babysitting, school programs, etc). 3

___ Check with the people responsible for helping you meet each need to make sure progress is being made. 4

___ Go to meetings with you at your child's school or other agencies or make phone calls when you need extra help to work with service providers. 5

___ Tell you where to get more information on your own about your child's disability, legal rights, parenting classes, financial assistance, parent support groups, etc. 6

___ Teach you how to get the services you need and how to talk to professionals to make sure they listen to your concerns and ideas about how to help your child. 7

___ Other (briefly describe): _____ 55

_____

- **If you checked one or more of the types of help listed in question 29, continue to question 30.**
- **If you checked none of the types of help listed in question 29, go to question 36.**

30. Is there one professional or more than one professional who provide the type(s) of help you checked in question 29? (Check one)

___ one professional 1
___ more than one professional 2

- **If you checked "one professional" in question 30, continue to question 31 in the next column.**
- **If you checked "more than one professional" in question 30, answer question 31 in the next column; then skip to question 36.**

31. This professional or professionals work for: (Check all that apply)

___ Your child's school 1
___ Education Service District (ESD) 2
___ County Mental Health Program 3
___ Adult and Family Services (AFS) 4
___ Children's Services Division (CSD) 5
___ Juvenile Services (probation department) 6
___ Other (name) _____ 55
___ Don't know 777

32. How long has this professional been working with you? (Check one)

___ less than 1 month 1
___ between 1 and 6 months 2
___ between 6 months and 1 year 3
___ more than one year 4

33. How often does this professional meet with you? (Check one)

___ at least once a week 1
___ about every 2 weeks 2
___ at least once a month 3
___ less than once a month 4

34. How much more time do you have for family leisure activities and personal time for yourself since this professional has been working with you? (Check one)

___ LESS TIME 1
___ SAME AMOUNT OF TIME 2
___ SOMEWHAT MORE TIME 3
___ A LOT MORE TIME 4

35. How helpful is the support you receive from this professional? (Check one)

___ NOT AT ALL HELPFUL 1
___ SOMEWHAT HELPFUL 2
___ HELPFUL 3
___ VERY HELPFUL 4

36. Overall, how successful are you at this time in getting the help your child and family need from your child's school and other organizations? (Check one)

___ NOT AT ALL SUCCESSFUL 1
___ SOMEWHAT SUCCESSFUL 2
___ SUCCESSFUL 3
___ VERY SUCCESSFUL 4

37. Overall, how satisfied are you at this time with the quality of your family's life? (Check one)

___ NOT AT ALL SATISFIED 1
___ SOMEWHAT SATISFIED 2
___ SATISFIED 3
___ VERY SATISFIED 4

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PART V: THIS SECTION GIVES YOU THE OPPORTUNITY TO PROVIDE US WITH ANY ADDITIONAL INFORMATION ABOUT THE SUPPORT YOUR CHILD AND FAMILY RECEIVE.

38. Please write your comments about the support your child and family receive.

Thank you for your help with this survey!

Return the survey in the enclosed pre-addressed and postage–paid envelope to:

Constance Lehman
Teaching Research Division
Western Oregon State College
Monmouth, OR 97361

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APPENDIX B

November 21, 1995

Dear Parent,

During the summer, you received a letter from us to tell you the results of the Family Support Survey that you participated in. In that letter, we also told you about the next step we are taking to explain to direct service providers and policy makers what effective family service coordination really means to families who have children with emotional or behavioral disabilities.

We are calling this effort the Family Service Coordination Study. The most important part of this effort is to make sure we interview those parents who stated in the Family Support Survey that they were receiving one or more of the seven parts of service coordination that were listed in the survey and that the support they were receiving was helpful. Since you were one of those parents, we are asking that you help us in our efforts to gather more indepth and specific information than we could in the survey.

The first step is to let us know if you are interested in finding out more about what it would mean for you should you participate in the study. In order to make sure family confidentiality is maintained, Constance will be permitted to contact you only if you complete and return the enclosed statement giving the Oregon Family Support Network permission to provide Constance with the information she would need to contact you. If you choose to be contacted, please read the informed consent statement carefully, sign the statement, and return it in the enclosed pre-addressed, pre-stamped envelope within the next week.

The findings from the Family Support Survey have been reported to many professionals in Oregon and across the nation, including the Governor's office, many of the Commissions on Children and Families, a wide range of professionals who work in education, mental health, child welfare, and juvenile justice, individual parents and family advocacy groups in other states. You and other parents are being heard. The Family Service Coordination study will provide a more indepth understanding of what it takes to effectively support families. We hope you choose to be part of this effort. Thanks again for your commitment to making life better for all children who have emotional or behavioral disabilities and their families.

Sincerely,

Judith Rinkin
Executive Director

Constance Lehman, Ph.D.
Assistant Professor
Teaching Research , WOSC

BEST COPY AVAILABLE

November 21, 1995

Dear Parent,

Please read carefully the information below. If you are considering participating in the Family Service Coordination Study, sign and date this form and return it in the enclosed pre-addressed and pre-stamped envelope.

To: The Oregon Family Support Network

As a parent who participated in the Family Support Survey conducted by Constance Lehman, I am interested in finding out more about the Family Service Coordination Study. I understand that the purpose of this study is to gain a more indepth understanding of what it takes to provide parents with effective help to coordinate services for their child and family.

I am interested in participating in the Family Service Coordination Study. However, I would like more information about how I would participate and how much time might be required on my part.

I understand that, by giving my consent to release my telephone number and mailing address to Constance Lehman, she may then contact me to answer my questions and schedule our first interview, should I decide to participate in the study.

STUDY ID_____

Permission to the Oregon Family Support Network to Release Contact Information

I give permission to the Oregon Family Support Network to provide Constance Lehman with my telephone number and mailing address so that Constance Lehman may contact me to talk about the Family Service Coordination study and how I would participate.

Parent Signature: _____

Date: _____

APPENDIX C

January 16, 1996

Family Service Coordination Study: Parent Interview Guide / Interview #1

I. Introduction

1. State the purpose of the study and the interview.
   [To understand better what effective family service coordination means]

2. Refer to project description and consent form parent completed previous to interview.

3. Explain process and schedule for receiving the stipend.

4. Reiterate how the information will be used, anonymity of the interviewee, child, & family.

5. Explain anticipated progression of the study, possible second interview, tentative date for next contact, "member checks."

II. Data Collection

1. Tell me a little about your child and your family [give examples of possible information if it is difficult for the parent to get started; share what you know from the questionnaire data].

2. If I ask you to tell me what "family service coordination" means to you in relation to getting needed help for your son/daughter, what would you say?

3. Over the years, who has provided this kind(s) of help?

   Of these people, who would you say has been the most helpful?

   Why would you say this?

   At this time, if there is someone helping you in these ways, who is the person(s)?

   Why would you say she/he is helpful?

4. Would it be alright with you if I contact _[name]__ to get her/his ideas about what effective family service coordination means?

5. If you could change three things about the way things have gone for your son/daughter and your family since you realized you needed help for your son/daughter, yourself, or your family, what would they be?

6. What else would you like to share that you think is important in order to understand what effective family service coordination means?

III. Closure

Complete the interview by providing information about the next steps. These may include contacting the nominated professional, scheduling a second interview, conducting a member check. In addition, reiterate the schedule for mailing the stipend.

Case Analysis Meeting Form

Date_____ Case_____

Recorder_____ Attendees_____

1. MAIN THEMES, IMPRESSIONS, SUMMARY STATEMENTS

2. EXPLANATIONS, SPECULATIONS, HYPOTHESES

3. ALTERNATIVE INTERPRETATIONS, EXPLANATIONS, DISAGREEMENTS

4. NEXT STEPS FOR DATA COLLECTION (follow-up questions, specific actions, general directions)

5. Implications for REVISION, UPDATING, OF CODING SCHEME